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Title

Illness beliefs of adolescents with CFS and their parents: The perceived causes of illness and beliefs about recovery

Running Head

Illness beliefs in adolescents with CFS

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Conflicts of Interest

TC is the author of several self-help books on chronic fatigue for which she has received royalties. KR has co-authored a book with TC called "Overcoming Chronic Fatigue in Young People".

Abstract

The objective was to explore beliefs about the causes of CFS in a cohort of adolescents with CFS and their parents, and to explore the adolescent's beliefs about recovery. Questionnaires were administered to a clinical cohort of adolescents (N = 104) and their parents (N = 102 mothers and 63 fathers), presenting to a specialist CFS unit. These included a question about causes of their illness. Adolescents were also asked about the projected timeline of their recovery from CFS. The most commonly endorsed causes of CFS by adolescents and their parents were a virus and/or contextual factors and stress. Adolescents and their parents were in close agreement about the causes of CFS. Most adolescents said they did not know how long it would take them to recover from CFS. Informing adolescents about the prognosis for CFS is an important aspect of treatment.

Background: Beliefs about the causes of an illness affect how individuals respond to the symptoms of that illness, and what treatments are seen as credible and acceptable. In adolescents, their beliefs are influenced by those of their parents, and their parents are gatekeepers to seeking and facilitating treatment.

Chronic fatigue syndrome (CFS)/Myalgic Encephalomyelitis (ME) is characterised by severe and debilitating fatigue which is not the result of ongoing exertion or secondary to another medical condition (1). In a contested and poorly understood illness, it would not be surprising for there to be a range of beliefs about illness causation. Previous studies have found that adolescents tend to attribute their CFS to physical causes like infections (2-4) and stress (5). In one study, over half said they did not know what had caused their fatigue (5). The narratives elicited using qualitative methodology reflected the complexity of CFS (2). Adolescents, by definition, are at the stage of developing autonomy and independence from their family of origin. Despite this, parental illness beliefs may be important in influencing their offspring's illness beliefs and coping (6). Little is known about how parental beliefs about the cause of CFS compare to those of their adolescent offspring with CFS.

In CFS, there is inconsistent information about prognosis (5), which is likely to impact on beliefs about recovery in adolescents and parents. In qualitative studies, adolescents with CFS talked about time passing as being helpful to recovery (4), and all expressed hope that they would get better (2). In adults with CFS, beliefs about prognosis have been found to be a significant predictor of post-treatment fatigue (7). However, adolescents' beliefs about recovery from CFS/ME in a help-seeking sample, presenting to specialist CFS services, have not been previously explored.

Objective: To explore the perceived causes of chronic fatigue syndrome (CFS) in adolescents and their parents, and to explore beliefs about recovery held by the adolescents.

Subjects: One hundred and fifteen adolescents, age 11 to 18 attended specialist CFS units in London, UK and met the NICE criteria for CFS based on clinician judgement during the recruitment period. Of these, 104 (90.4%) participated, 69% female, mean age 15.07 years, S.D. 1.69. 102 mothers and 63 fathers completed questionnaires. .

Method: Adolescents completed questionnaires including a question about the causes of their illness, giving fixed choice options (virus, activity – too much exercise/too little exercise, and context – environment, family problems, problems at school, problems with friends, stress), with respondents selecting all that applied. Adolescents were also asked ‘how long do you think it will take you to recover from your CFS?’. Parents completed questionnaires, including a question about the causes of their offspring’s illness, mirroring that posed to the adolescent. Appropriate ethical approvals were secured for conducting this study (NHS LREC ref 08/H0807/107).

Results: Around half of adolescents (50.4%) attributed their CFS to a virus and/or to stress and contextual factors (50.4%). Approximately two thirds of parents (63.5% of fathers and 63.7% of mothers) attributed their offspring’s CFS to a virus, and similarly, around two thirds of parents (66.7% of fathers and 72.5% of mothers) attributed their offspring’s CFS to stress and contextual factors. Around a quarter of adolescents (26%), 35% of fathers, and 42.2% of mothers attributed the CFS to activity (see table 1).

Table 1. Table showing frequency with which participants and their parents endorsed the suggested causes for their CFS – data shown as N (%)

	Adolescents (N = 104)	Mothers (N = 102)	Fathers (N = 63)
Environment	13 (11.3)	24 (23.5)	12 (19)
Problems at school	21 (18.3)	30 (29.4)	20 (31.7)
Problems with friends	11 (9.6)	19 (18.6)	14 (22.2)
Family Problems	13 (11.3)	14 (13.7)	7 (11.1)
Stress	53 (46.1)	66 (64.7)	38 (60.3)
A virus	58 (50.4)	65 (63.7)	40 (63.5)
Not enough exercise	6 (5.2)	14 (13.7)	9 (14.3)

Too much exercise	22 (19.1)	33 (32.4)	14 (22.2)
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Apart from the cause 'not enough exercise', the causal attributions adolescents made for their CFS were significantly correlated with those made by their mothers (environment, $r = .33$, $p = .001$; problems at school, $r = .44$, $p < .000$; problems with friends, $r = .64$, $p < .000$; family problems, $r = .54$, $p < .000$; stress, $r = .36$, $p < .000$; virus, $r = .45$, $p < .000$; too much exercise, $r = .45$, $p < .000$; not enough exercise, $r = .02$, $p = .828$) and by their fathers (environment, $r = .26$, $p = .048$; problems at school, $r = .47$, $p < .000$; problems with friends, $r = .43$, $p < .000$; family problems, $r = .68$, $p < .000$; stress, $r = .38$, $p < .000$; virus, $r = .45$, $p < .000$; too much exercise, $r = .38$, $p = .003$; not enough exercise, $r = .14$, $p = .304$). Apart from the cause 'too much exercise', the causal attributions made by mothers were significantly correlated with those made by fathers (data not shown).

One hundred and three adolescents responded to the question asking how long they thought it would take them to recover from CFS, with 87 (84.5%) indicating that they did not know, 8 (7.8%) saying > 12 months, and 8 (7.8%) endorsing an option of < 12 months.

Conclusion: In this cohort of adolescents presenting to a specialist CFS unit, approximately half of adolescents, and two thirds of mothers and fathers, endorsed either a virus and/or contextual factors and stress as a cause of the adolescents' CFS. Adolescents and both their mothers and their fathers appeared to be in close agreement about the causes of CFS, and mothers and fathers appeared to agree with one another. Thus, family narratives about the causes of CFS seem to be relatively consistent. The vast majority of adolescents with CFS did not know how long it would take them to recover from CFS.

Consistent with previous research (8, 9), the views of adolescents about what might have caused their CFS were complex and multi-factorial. The pattern of endorsement of psychological causes (i.e. stress) as well as physical causes of CFS in this cohort adds to the existing literature, which has mainly been based on adult samples.

Attributing CFS to a viral cause may be advantageous because the explanation is easy to understand and to explain to others, and it may also be self-protective as it precludes guilt, blame or social stigma that may be associated with alternative explanations. However, the problem of attributing CFS to a viral cause is that it may result in feeling helpless around self-efficacy for recovery (8).

Importantly, the current study shows that family members tend to agree on the perceived causes of CFS. This extends the findings of Clements et al (9), who reported that 27% of adults thought that they had developed an understanding of their illness through the influence of others (i.e. talking to others, being 'diagnosed' by a family member or friend, and knowing about others with similar symptoms).

Given that beliefs about prognosis have been shown to be important in determining outcome in adults with CFS, (7), informing adolescents with CFS about the evidence, which indicates good recovery rates with treatment (10) is an important intervention for specialist services to undertake.

The strengths of the study are that data was collected from both parents as well as young people. Limitations include the cross sectional nature of the study in the context of a specialist service and the lack of data about parental beliefs about prognosis. Future studies should examine the extent to which causal attributions predict outcome and qualitative studies are needed to explore illness narratives fully.

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